



Testing the Feasibility of Screening Children for FASD Risk in Early Intervention Settings

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Building FASD State Systems
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Institute for Health and Recovery

IHR is a statewide service, research, policy, and program development agency. Our mission is to develop a comprehensive continuum of care for individuals, youth, and families affected by alcohol, tobacco, and other drug use, mental health problems, and violence/trauma, based on the principals of:

- Establishing collaborative models of service delivery
- Integrating gender-specific, trauma-informed and relational/cultural models of prevention intervention, and treatment
- Fostering family-centered, strength-based approaches
- Advancing multicultural competency within the service delivery system



Project Fetal Alcohol Screening for Today (FAST)

- To prevent FASD through prenatal alcohol screening
- **To identify and treat children with an FASD in Early Intervention settings**
- To provide FASD health education to 2 SUD treatment programs for pregnant women
 - Funded by the Substance Abuse and Mental Health Services Administration's Fetal Alcohol Spectrum Disorders Center for Excellence



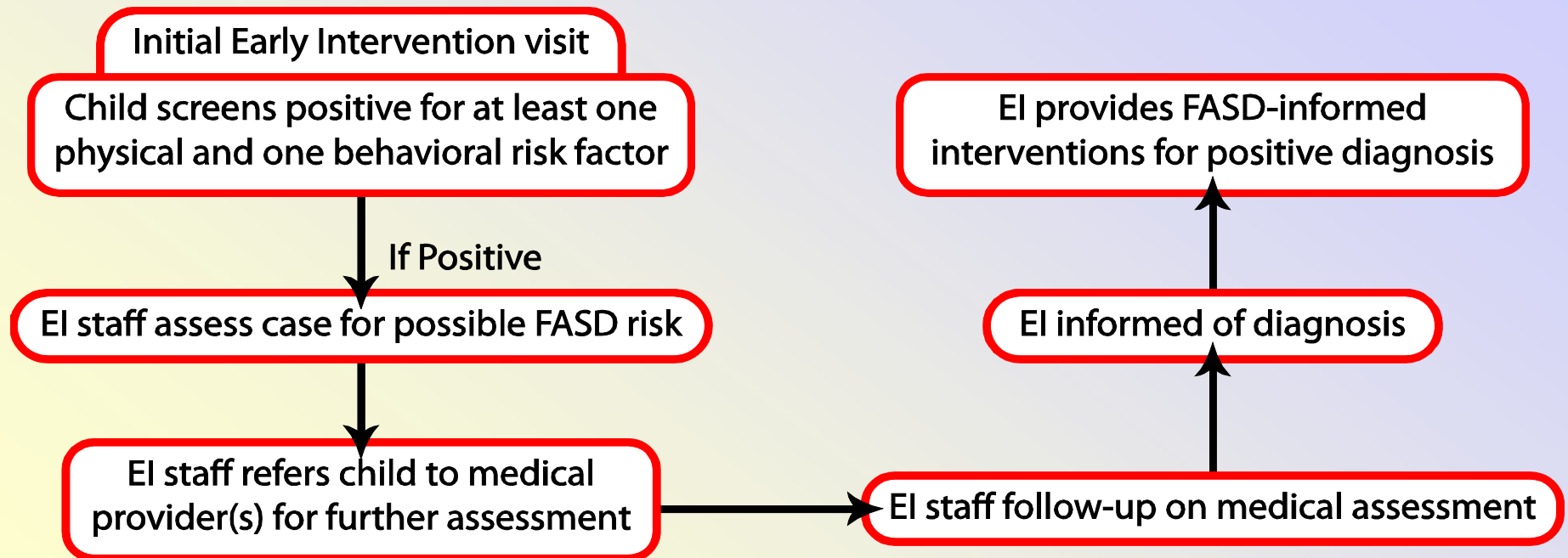
Part C of Public Law 108-446-34 CFR Part 303

Early Intervention Program for Infants and Toddlers with Disabilities





The FASD and EI Vision





Why Not Pediatricians?

- Reluctance to take Maternal Alcohol Histories
- Not convinced of Utility of Diagnosis
- Low rate of developmental screening due to time, reimbursement & staff issues





Methods



Project FAST

FASD Screening Tool

Designed by:

- Clinical geneticist with expertise in FASD
- Pediatrician
- Pediatric psychiatrist
- Developmental psychologist with expertise in FASD
 - Barbara Morse, Ph.D.



Project FAST FASD Screening Tool **(Risk Factors, Birth-3)**

Was this child prenatally exposed to alcohol?

☐ Yes ☐ No ☐ Unsure ☐ No Answer

**Does this
child have:** (Check all that apply)

☐ Small head
circumference _____

☐ Smooth philtrum

☐ Alcohol use during
pregnancy

Birth-Three

☐ Poor sleep
patterns

☐ Difficult to feed

☐ Hard to soothe

** One or more Factors from each box indicates risk of FASD; referral recommended*



Getting “Buy In” Early Intervention Sites

Innovators/Early Adopters

- Steering Committee Meetings included:
 - EI Site Directors
 - Developing implementation protocols
 - FASD training
 - Problem-solving and addressing barriers





Provide Training

- Alcohol and pregnancy, FASD 101
- Stigma and Addiction
- FASD risk factors
- Utility of diagnosis
- Talking to parents of children with an FASD
- FASD Screening
 - Disposable paper tape measures
 - Table of age- and gender-specific 10th %tile head circumference measurements
 - Lip-Philtrum Guides



Taking Maternal Alcohol Histories





Engraving by
William Hogarth

Gin Lane

1750





Stigma, Addiction & Parenting Women

- Stigma, guilt & shame
 - Low social tolerance of addiction in women, judgmental attitudes & punitive approaches
 - Sexualized image: seen by others as promiscuous whore or lush
 - Stereotype of bad, uncaring mother
- Hopelessness, helplessness, low self-esteem
- Anger & blame from caregivers
- Lack of trust – fear loss of children



Stigma, Addiction & Parenting Women

“What gets me angry is that these patients come in and they demand a lot of attention and a lot of work and then in some respects, it takes away from the medical care that the other patients get who did the right thing... and everyone is, like, being drawn away to help some drug addict who rolls in off the street in stress because she got high on crack and never went to clinic. Sometimes I think, ‘the hell with her.’ I want to take care of the other patients.”

-Obstetric Resident, March of Dimes



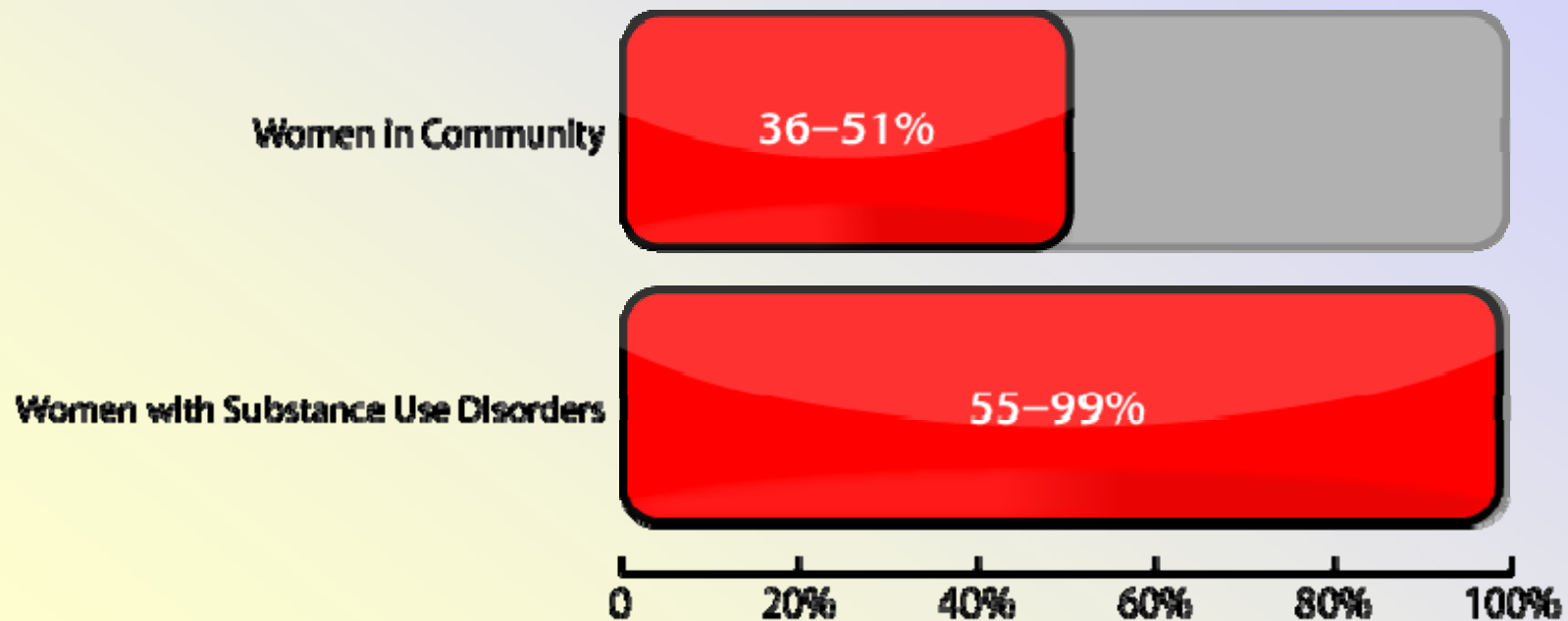
Maternal Alcohol History

- Maternal Risk Factors for FASD
- Profile of 80 birth mothers of children with FAS (*Astley et al, 2000*)
 - 96% had 1-10 mental health disorders
 - 77% PTSD
 - 95% physically or sexually abused
 - 79% reported a birth parent with an alcohol problem



Substance Use Disorders, Women & Trauma

Women in SUD treatment report a higher lifetime history of physical/sexual violence than women in community samples



Najavits et al., 1997



What is a Standard Drink?

**1 bottle
of wine
cooler
12 oz.**



**1 can of
ordinary
beer or
ale
12 oz.**



**1 single shot
of spirits:
whiskey,
gin, vodka
1.5 oz.**



**1 glass
of
wine
5 oz.**



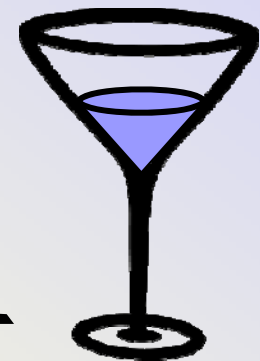
**1 small
glass
of
sherry
4 oz.**



**1 small
glass of
liqueur,
aperitif
4 oz.**



**1 small
glass of
martini
1.5 oz**





Culture and Alcohol



ETOH



Training Materials

- *The Effects of Alcohol Consumption on a Developing Baby*
 - An informational brochure to be given to parents of children referred for further FASD assessment
- *Strategies for Addressing FASD, Birth-3*
- *Strategies for Addressing FASD Throughout the Lifespan*



Linkages and Training

- Two large health systems to assist in pediatric referrals for specialist assessment
- Local residential alcohol disorder treatment programs for pregnant and post-partum women, some of whom received services from participating EI programs



Head Measurements





The Three FAS Facial Features

- 1) Short Palpebral Fissures
- 2) Smooth Philtrum
- 3) Thin Upper Lip



Lip-Philtrum Guide 1



Lip-Philtrum Guide 2



Diagnosing Fetal Alcohol Syndrome

- Prenatal maternal alcohol use
- Growth deficiency
- Central nervous system abnormalities
- Dysmorphic features
 - Short palpebral fissures
 - Indistinct philtrum
 - Thin upper lip





Stoler J, Holmes L. J Pediatr 1999; 135:430-6.



Long flat
philtrum

Thin
vermilion

Stoler, 2005



Outcomes

Infants & Young Children

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The Feasibility of Screening for Fetal Alcohol Spectrum Disorders Risk in Early Intervention Settings A Pilot Study of Systems Change

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Deborah Gurewich, PhD; Barbara Morse, PhD*



Results:

FASD Screening of Children in EI

	Screened		Not Screened		Total (N)
	<i>n</i>	%	<i>n</i>	%	
Site A	173	41%	241	59%	414
Site B	472	75%	159	25%	631
Site C	516	59%	335	41%	851
Total	1161	61%	735	39%	1896



Breakdown of Affirmative Answers to Each of the Six Risk Factors

	Number of children with positive response	% of total sample (<i>n</i> =1,161)
Physical		
Small head circumference	7	1%
Smooth philtrum	3	>1%
Alcohol use during pregnancy	63	5%
<hr/>		
Behavioral		
Poor sleep patterns	28	2%
Difficult to feed	24	2%
Hard to soothe	19	2%
<hr/>		
Any of the risk factors	92	8%
At least one physical & one behavioral risk factors	19	2%



Table 4: FASD Risk and Referral for Further Assessment

Of clients screened, number and percentage who screened at risk for FASD

Of clients screened at risk for FASD, number and percentage referred for further assessment

Site A (<i>n</i>=173)	12	7%	Site A (<i>n</i>=12)	10	83%
Site B (<i>n</i> =472)	5	1%	Site B (<i>n</i> =5)	3 ¹	60%
Site C (<i>n</i> =516)	2	<1%	Site C (<i>n</i> =2)	0	0%
Total (<i>n</i>=1161)	19	2%	Total (<i>n</i>=19)	13	68%



	Total Sample Screened (N=1259)		Sample Screened Positive for FASD (N=20)	
Age of Child				
1 to 12 Months	489	40%	8	40%
13 to 24 Months	448	36%	3	15%
25 to 36 Months	301	24%	9	45%
Over 36	1	< 1%	0	--
Total	1239	100%	20	100%
Race				
White	368	30%	3	15%
African-American	271	22%	7	35%
Latino/Hispanic	486	40%	8	40%
Asian	37	3%	1	5%
Other	64	5%	1	5%
Total	1226	100%	20	100%
Family Status				
Child Welfare Custody	42	3%	4	21%
Adoption (International)	10	1%	1	5%
Adoption (Domestic)	12	1%	1	5%
Birth Child	1140	93%	6	32%
Other (Legal guardian)	27	2%	7	37%
Total	1231	100%	19	100%



Implementation Challenges

- Screening roles & head circumference
- Maternal Alcohol Histories
- Champions v. frontline staff
- Time for training
- Primary care referral process
- Project funding



Lessons Learned

- Select a single staff person to complete screening
- Practice Maternal Alcohol Screening
- Insert FASD screening into existing EI intakes
- Provide ongoing technical assistance to support screening fidelity



Lessons Learned

Site differences affecting implementation

- Sites B and C initially experienced more challenges with implementation
 - Larger staffs
 - Less FASD experience
 - Less training time



Site Differences Affecting Implementation

Site A

- More time available for project training
 - More positive perception of benefit through prior FASD experience
 - Entire staff = “FASD Champions”
- target population with high risk factors for
- Poverty, transience, trauma histories, mental health disorders, stress, and tobacco use
- Early embrace of protocols combined with this population resulted in 68% of the positive FASD screens from all sites



Lessons Learned

- Resources needed to screen in EI:
 - Trainer, time & training
- Replication efforts would benefit from cost-free cross-training between:
 - EI sites
 - Designated pediatricians who would become ‘FASD-informed’
 - FASD diagnosticians
 - Alcohol disorder treatment



Lessons Learned

- Protocols are transferable to other agencies who serve families with low SES and other FASD risk factors:
 - Homeless shelters
 - WIC
 - Child care and pre-school centers
 - Community health centers
 - Substance use disorder family treatment programs



FASD Prevention



"I'll have an ounce of prevention."



Massachusetts FASD Prevention: Recent SBIRT Initiatives

- Community Health Centers (CHC)
 - + New FASD Prevention Toolkit
- School-Based Health Centers
- Batterer's Intervention Groups
- Deaf/Hard of Hearing
- Emergency Rooms, Hospitals, CHCs
 - SAMHSA funding
- Coming next: Clergy!



Resources

- SAMHSA FASD Center for Excellence:
fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org/
- National Clearinghouse for Alcohol and Drug Information: ncadi.samhsa.gov